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ABSTRACT

The booklet describes the Association for Retarded Citizens' (ARC's) goal of coordinating efforts to seek a cure for mental retardation. Cures are defined as any intervention that would significantly increase intellectual functioning and adaptive behavior beyond the upper level of retardation. It is explained that because of the variety of causes for retardation, the search must involve multiple cures. The notion of prevention as one type of cure is addressed. Recent advances in scientific research (on such aspects as enzymes, possible regeneration of nerve cells, and addition of brain hormones) are noted. A conference on current and future research is summarized, and developments reported. The booklet concludes with a series of questions and answers about ARC's position on the issue. (CL)

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MENTAL RETARDATION

THE SEARCH FOR CURES

Research Monograph Number Seven

Association for Retarded Citizens

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MENTAL RETARDATION: THE SEARCH FOR CURES

I. A New Major Goal for the ARC

The past few years have marked the beginning of a new era of discovery. Rapid advances in such fields as electronics and computer science have opened challenging avenues of study, and greatly accelerated the development of knowledge in other areas. Space-age technology has benefited the biological sciences in a number of different ways: Researchers are gaining new insight into the science of genetics and the mapping of chromosomes. . . Nuclear medicine has become a standard tool in the treatment of many conditions. . . Significant steps have been taken toward unraveling the complexities of cloning. . .

Perhaps one of the most important biological advances of the past decade is an increased understanding of the physiology of the brain. We are learning more and more about how the brain works, and what it can do. Recent progress in this field provides the basis for enhancement of mental functioning, and reversal of disorders and conditions associated with mental retardation. Potentially fruitful areas of study include: the regeneration of nerve cells in both the brain and the spinal cord. . . the concept of a "cerebral pacemaker" designed to reverse disturbing electrical activity in the brain. . .

Since its inception, the Association for Retarded Citizens has taken a leading role in furthering the dual goals of amelioration and prevention — the enhancement of the lifestyle and potential of mentally retarded persons, and the prevention of mental retardation in future generations. Now, in line with current advances in the scientific field, the ARC has adopted a third major goal: stimulation of a coordinated effort to seek cures for mental retardation. The Association believes this goal is both a logical and vital extension of its past and present directions.

In pursuit of this new goal, the Association does not wish to generate false hopes or unrealistic expectations to the families of mentally retarded persons, or to the public in general. Neither does the ARC wish to give the impression that long-established goals of prevention and habilitation will in any way be neglected.

Adoption of this goal marks a major turning point in both the Association's internal stance and in its national posture toward the condition of mental retardation. It is an important change, and one that calls for careful reevaluation of the way mental retardation, and mentally retarded persons, are viewed.

Mental retardation has traditionally been defined as irreversible. In fact, this irreversibility is one of the points we have used to distinguish so-called mental illness form mental retardation. Nearly every professional in the field has assumed or been taught that while we can better the lifestyles of many mentally retarded persons, and prevent many instances of this handicapping condition, cures are out of the question.

Acceptance of this "dead end street" has fostered several understandable attitudes on the part of both the scientific community and the general public. First, we have established an overall feeling of hopelessness regarding mental retardation. Time has a way of solidifying such assumptions and, eventually, turning them into "facts." The "fact" of irreversibility has been with us so long, it has generated an almost automatic counter-reaction: reluctance to accept the possibility of cures, and suspicion of those who claim advances (or even the possibility of advances) in this area.

We are faced, then, with several deeply ingrained premises that could hamper pursuit of this new goal: Since mental retardation cannot be cured, there is no need to search for cures. Thus, those persons or agencies who do look for cures are likely to be misguided researchers, or out-and-out charlatans.

There is, of course, precedence for these attitudes. Historically, those ideas and proposals which conflict with established beliefs are often greeted with reservation, fear or skepticism. Louis Pasteur, discoverer of the rabies vaccine, was ejected from the French Academy of Sciences when he proposed the radical theory that germs caused diseases. A German physicist argued that railway trains traveling at speeds in excess of twenty miles per hour would rupture the blood vessels of passengers. Both of

these events occurred in the 1800s, but our own century is not without its skeptics. Not too many years ago, some authorities stated that pilots who attempted to break the sound barrier might be "turned into jelly."

Certainly, not all those persons who are scorned for their efforts become ultimately vindicated. Many, with the best of intentions, have simply taken a wrong turn in their attempt to better the human condition. Still, those who are right literally revolutionize our lives, and change our whole manner of looking at the world.

Parents, professionals and others involved in the field of mental retardation will recognize the new goal as a practical extension of the Association's continuous policy of exploring directions that might eventually benefit mentally retarded persons or lessen the incidence of mental retardation. The Association for Retarded Citizens has often led the way in pointing out new possibilities for research and programmatic services. Many of these "possibilities" of the past are the standard, accepted practices of today.

An Important Definition

Promoting the search for cures is both an exciting and a challenging goal for the ARC. However, it is a search that cannot be properly pursued without a true understanding of the problems at hand. In considering the search for cures, it is important to remember that:

(1) Mental retardation is the result of a great many conditions and disorders. Although over 250 causes have been identified, many causes are still unknown.

(2) It stands to reason, then, that it is both inaccurate and impractical to speak of the search for a single "cure" for mental retardation. The goal must include the consideration of different cure possibilities for a number of different conditions.

What does "cure" really mean? What is the difference between a preventive measure and a cure? Prevention generally means that some steps have been taken to keep a disease or disabling

condition from happening. A cure, on the other hand, is the reversal or elimination of a disease or disabling condition that has already occurred in an individual. For our purposes here, we might define cures for mental retardation as:

> Any intervention that significantly increases intellectual functioning and adaptive behavior above the upper level of the mental retardation range.

Mental Retardation: A Special Case

We already know how to prevent certain forms of mental retardation. For example, through early screening and dietary intervention we can prevent the mental retardation associated with over a dozen genetic diseases. And, there are some measures currently in use that cross the line between prevention and cure. In some of the inborn errors of metabolism, initiation of a corrective diet may actually follow the onset and produce a reversal or elimination of symptoms characteristic of mental retardation.

Mental retardation has facets in common with other disabling conditions. On the other hand, this particular condition has some specific characteristics of its own. For instance: In many cases of mental retardation — perhaps in the majority of cases — there is no visible evidence of neurological damage. In other words, the brain of most mentally retarded persons cannot be distinguished from that of persons of "normal" intelligence. This holds true in both the living brain and in post-mortem examinations, such as microscopic evaluation or biochemical analysis. Clearly, this is not the case with such generally identifiable conditions as blindness, cancer or heart disease, where there is obvious pathological damage.

Mental retardation may be regarded as a set of symptoms associated with some condition, disorder, or developmental history, rather than a disease. The search for cures seeks to stimulate research which will eliminate the symptoms of mental retardation by reversing the associated disorders or delayed development which give rise to the symptoms.

The Association's goal with respect to cures is twofold:

(1) To foster research and other activities that show promise of developing curative measures in the field of mental retardation.

(2) To accurately inform the ARC membership, the families of mentally retarded persons, mentally retarded persons themselves, professionals in the field of mental retardation and related fields, and the general public of the true nature of our goal, and the manner in which the search for possible cures is related to the various conditions of mental retardation.

In Summary

★ The Association for Retarded Citizens has adopted a third major goal: stimulation of a coordinated effort to seek cures for mental retardation.

★ Since there are many causes of mental retardation it stands to reason that this goal will involve a search for multiple cures.

★ Due to the nature of mental retardation, there is a fine line between the areas of prevention and cure. By prevention, mental retardation is kept from occurring. By cures, mental retardation is eliminated after it has occurred. Treatments which in the past have been called prevention should now properly be called cures.

II. Some Reasons for Optimism

While caution is the key word in the search for cures, there are a number of current areas of study which suggest hopeful directions for scientific research. A few of these include:

★ The absence of certain enzymes — or body chemicals — from the system leads to nerve or brain damage. One group of researchers is studying "enzyme replacement therapy" in an effort to supply these missing chemicals to the body. Until recently, these

efforts have been hampered by the fact that substances introduced into the bloodstream will not directly enter the brain. Now, a technique has been discovered which allows the introduction of treatment enzymes.

★ Research has documented the fact that damaged nerve cells in both the brain and the spinal cord are replaced by "sproutings" from associated cells. Since this process does take place naturally, scientists working in this area feel there might be a way to initiate regeneration in specific target areas. Related research has shown that damaged nerve insulation material can be restored by transplanting insulation-growing cells to the impaired area.

★ Some research suggests that the introduction of additional quantities of brain peptides, or hormones — which occur naturally in the brain — may enhance a mentally retarded person's ability to direct his attention to the learning process.

In March of 1980, the Association for Retarded Citizens and the President's Committee on Mental Retardation sponsored a conference titled "Mental Retardation: The Search for Cures" at Sea Island, Georgia. On hand were approximately fifty scientists from various fields of study, including endocrinology, special education, psychiatry, genetics and neurosurgery. The general conclusion of the participants was most encouraging:

> "There is certainly reasonable cause to believe that during the next two decades some startling advances will be made in the area of secondary preventions or cures..."

Quite naturally, the optimism of these participants was tempered by caution. Most of the current and future studies discussed here are still in various stages of development. It seems likely that many of these areas of research will show significant results — and even exciting breakthroughs. The complexity of the problem will call for understanding and close cooperation

between biomedical and behavioral researchers in both basic and applied fields of study.

Mental Retardation: The Search for Cures — Conference Overview on Current and Future Research

Conference Presenter Dr. Verne S. Caviness, Director of the Southard Laboratories of the Eunice Kennedy Shriver Center for Mental Retardation in Boston, noted that complex cellular events take place during prenatal development of the human brain. A clear understanding of the timing and nature of these events is essential before consideration can be given to intervention in instances where brain development has gone awry. One can currently predict possible intervention tactics based on the demonstrable lesions which outline the stages of brain maturation and when the developmental interruption occurred. The nature of what corrective factors or helpful treatments are possible awaits the time when the brain yields more of its secrets. He pointed out that while we do not yet know the causes of damage during this period, we can now pinpoint the precise stage during which the damage occurred. Thus, we are now able to search for those causes, and lessen their damaging effects.

The research in which Dr. Caviness is involved underscores the internal points of brain cell development where known syndromes (e.g., brain malformations) occur. This will help us focus more sharply on possible internal-external causes — hopefully leading, as with rubella, to the discovery, study, and eventual prevention of other major causes of mental retardation. Truly the era of the scientific study of the biological basis of the symptom of mental retardation has fully arrived! Focus on the specific processes of illness will lead to further understanding and eventually curative milestones.

Dr. Dominick P. Purpura, Director of the Rose F. Kennedy Center for Research in Mental Retardation and Human Development, discussed the importance of current and future research thrusts to better understand those disorders which specifically attack the cells of the brain. He noted that our knowledge of what occurs during this cellular destruction has

greatly advanced our understanding of how that action takes place. Knowledge of the nature and method of cellular damage should lead us to the reasons for destruction, and the possibility of intervention that might reverse this process.

An analogous area of research is Alzheimer's Disease (a specific and progressive destruction of brain tissue which produces what is commonly termed "senility" in elderly individuals) in which the different early researchers were unaware that they were working on the same process of brain destruction. More recently, it has become clearly noted that the underlying processes are identical in "severity" and are secondary to specific nerve cell damage (the "how") and we (hopefully) will soon understand the "why" of Alzheimer's Disease. Further research on the "why" dimension will lead to possible treatment interventions to reverse this what-how-why process of brain destruction and/or maldevelopment.

Both Drs. Caviness and Purpura underscored the fact that the study of brain malformation has become a dynamic area of research. They felt, along with other conferees, that we have finally begun serious scientific study of the biological causes of mental retardation.

Dr. Gary Lynch, Professor and Chairman of the Department of Psychobiology at the University of California at Irvine, discussed the chemical inducement of learning experiences. He noted that electrical stimulation of the hippocampus, an area directly above the cavities found in each side of the brain, produces lasting physiological changes — reflected in the increased ability to store and process learned behaviors. More importantly for our purposes, experiments with animals show that learning experiences consistently produce new cell branching in damaged areas of the hippocampus. Dr. Lynch feels that a very potent biochemical action may be at work here — one that is far different from the more familiar electrical process of the central nervous system.

Regeneration of nervous tissue was the subject addressed by Dr. Ayub K. Ommaya, Chief of Applied Research in Surgical Neurology of the National Institute of Neurological and Communicative Disorders and Stroke. Experiments with animals

have shown various degrees of nerve tissue regeneration after neuro-surgical nerve sheath grafting. In addition, brain tissue transplants in rats have proved quite successful — the transplanted tissue became neurochemically active, secreting the substances necessary for transmission between nerve cells.

The full integration of transplanted tissue into the brain is indeed an important breakthrough. We are a long way from utilizing this process in humans, but the experiments themselves mark an important milestone in future efforts to "rebuild the brain."

Dr. Aubrey Milunsky, Director of the Genetics Division of the Eunice Kennedy Shriver Center for Mental Retardation, discussed current progress in reversing inborn errors of metabolism. Dr. Milunsky noted that thirty to forty disorders which produce mental retardation can now be cured, and pointed out that advances in prenatal diagnosis hold great promise for reversing genetic errors during pregnancy. A great deal of progress has been made in this area of research — one once believed to be "next to hopeless."

Another aspect of genetics was presented by Dr. Park S. Gerald, Chief of the Clinical Genetics Division of the Children's Hospital Medical Center in Boston. Dr. Gerald stated that genetically caused body and central nervous system malfunctions which originate during the prenatal period may continue activity after birth. If this is so, treatment and cure of such disorders may be possible shortly after birth.

Techniques for blocking or altering abnormal gene-enzyme activity are rapidly being perfected. We can now locate, isolate and substitute abnormal gene-enzyme patterns through "genetic engineering." Down Syndrome is a most likely target for such procedures. Chromosome mapping techniques are already quite advanced — at some future date, we may be able to reverse the adverse effects of this syndrome. Successful research in this area alone would have a staggering effect on a large portion of our mentally retarded population.

Dr. Abba Kastin, Chief of the Division of Endocrinology at the Veterans' Administration Hospital in New Orleans, reported on

advances in the field of peptide research. Peptides are strings of amino acids occurring naturally in the brain and elsewhere in the body. Because of their profound effect on the central nervous system, peptides might someday be used in both diagnosis and treatment of mental retardation. Tests have already shown promising results. Recent clinical studies with mentally retarded adults in vocational settings indicated that certain learning deficits traditionally thought to be irreversible can be modified through the use of peptides. It is still too early to weigh the real value of peptide studies, but there is clearly enough positive data on hand to justify a rapid expansion of research efforts.

Dr. Kenneth C. Davis, Chief of the Psychiatric Services of the Veterans' Administration Hospital in the Bronx, New York, noted that neurotransmitter enzymes and related central nervous system enzymes play a key role in information processing and mental retention. Clinical tests on patients with senile dementia have been very promising. Though little research in this area has been done with mentally retarded persons, it is highly possible that such neurotransmitter deficiencies do play an important role in mental retardation — especially early in life.

Dr. Earl C. Butterfield, University of Washington in Seattle, noted:

> "Because there are some very promising trends in the field of behavior modification and cognitive development, the heady possibility exists that behavioral science is on the threshold of delivering ways to improve human thinking and memory to the point that it may become possible to claim cures for the cognitive deficits that lead us to currently consider some people mentally retarded..."

Dr. Butterfield pointed to encouraging developments in the various fields of behavioral science. Previous barriers, he noted, no longer seem insurmountable. Now, it seems quite reasonable to look for the establishment of efficient learning environments within the next ten years — environments which will greatly accelerate the intellectual and social growth of mentally retarded citizens.

Dr. Butterfield and many other conference participants stressed the importance of professionals from various fields working closely together to further research goals. Those concerned with basically internal or biological causes of mental retardation are discovering they have a great deal in common with environmental and behavioral researchers — and vice versa. The possibilities of new, combined thrusts toward cures in mental retardation was one of the most exciting vistas of the Sea Island Conference.

Dr. Sidney Bijou, Professor Emeritus of Special Education at the University of Illinois and Adjunct Professor of Psychology and Special Education at the University of Arizona, discussed a strategy for dealing with mild and moderate mental retardation in young children. Dr. Bijou's premise involves behavioral training of parents and teachers to provide children with increased opportunities for both intellectual and academic achievement. Results of this strategy have already shown marked successes in effecting major changes in parent and teacher practices. When these procedures are used with very young mildly retarded children, the subjects show definite intellectual and social adaptive progress by the end of the fourth grade — so that they test within the normal range of development.

Dr. Bijou strongly believes that application of this approach to the basically similar learning problems of moderately retarded children will enable these children to function in the upper mild or borderline levels of intellectual development. It is important to emphasize the fact that current intervention programs with mildly retarded children have often resulted in essentially normal levels of functioning. In other words, we are now able to cure many individuals in this very large grouping — which includes seventy-five percent of the mentally retarded population!

Working Together

As mentioned earlier, one of the high points of the Sea Island Conference was the exchange of ideas, knowledge and viewpoints from a number of different perspectives. This type of

open, interscientific forum is essential to the realization of our goal of curing complex mental/behavioral disorders.

Conference participants also noted that scientists directly involved in mental retardation research benefit enormously from the contributions of biomedical and behavioral researchers in other fields. Many of these persons are engaged in work which could profoundly affect millions of mentally retarded citizens.

A noteable example is Dr. Norman Anderson, head of the Molecular Anatomy Program at Argonne National Laboratory near Chicago. Dr. Anderson has proposed a bold — and controversial — effort to increase knowledge in the biomedical field — a search that would lead eventually to a detailed understanding of human anatomy on the molecular level. His proposal involves the development of a Human Protein Index, a comprehensive roster of the estimated 30,000 different kinds of protein in the human body. Since only 1 to 2% of these proteins have been identified to date, Dr. Anderson's task is clearly both staggering and vitally important.

When completed, his list could conceivably identify all proteins by function and location. Since genes dictate the manufacture of proteins, the list might locate these genes on specific chromosomes. Such an accomplishment could give us a key to the causes of genetic diseases — an enormously useful tool for medical science.

An Approach to Tomorrow

Clearly, there is a growing body of evidence that indicates a number of cures for mental retardation may be discovered within the next few decades. Rapidly emerging knowledge from the behavioral, biomedical and allied fields could, in the near future, have an enormous impact on the lives of mentally retarded citizens.

III. A Search For Cures: Questions and Answers

Many people have asked questions about the goal to encourage the search for cures. While reactions to the goal have been most enthusiastic, there is still some misunderstanding and

confusion regarding both the nature and complexity of this thrust. Below some representative questions are answered which have occurred. In some cases the questions and answers will summarize points made previously in Parts I and II for the readers' convenience.

Q: Does the Association's new position on cures mean that we can now cure mental retardation?

A: Some interventions formerly thought of as prevention should really be considered cures. We are adopting the position that we should try to find cures on a broad scale. This position has long been the stance of agencies and organizations working for cures for cancer, heart disease, "mental illness" and other diseases and disabilities. The ARC has now adopted a similar goal.

Q: The ARC has been around a long time. Why did they suddenly decide to look for cures?

A: It wasn't really a "sudden" decision. Until quite recently, there was very little evidence that various forms of mental retardation might be cured. Relatively new advances in research have shown us that there is good reason to believe a number of cures for mental retardation could be discovered in the next few decades.

Q : Why are these advances in research just now coming to light? We've been making significant progress with other diseases and disabling conditions for some time now.

A: The various types of mental retardation differ markedly from conditions such as cancer, heart disease and blindness. In the majority of cases of mental retardation, there is simply no visible evidence of neurological damage. In other words, there is nothing scientists can "see" that could cause mental retardation — except in very extreme cases.

Clearly, this lack of visible, physical damage has hampered advances in the field for some time, and reinforced the concept that no cures for mental retardation could be discovered.

Q: What has happened to change that concept?

A: The advent of the space age played a big part in changing attitudes toward the possibility of cures. When the Association for Retarded Citizens was founded in 1950, computer science, genetics, molecular medicine and many other areas of study we now take for granted were in their infancy. Incidentally, the ARC has played a significant role in advancing the "state of the art" that has placed us on the threshold of the search for cures. ARC research thrusts in the areas of prevention and programming have helped open the door to possible curative research efforts.

Q: Doesn't this "search for cures" offer a false hope to the families of mentally retarded persons? Up to now, parents have been told their mentally retarded children have an irreversible condition.

A: The ARC does not wish to generate false hopes or unrealistic expectations. In all probability, most of today's mentally retarded citizens will not be cured. That fact alone is reason enough to earnestly begin the search for answers. The Association for Retarded Citizens is well aware of the fact that the adoption of the search for cures will quite naturally lead many people to focus on the end of its quest, rather than the beginning. We intend to make every possible effort to inform the families of mentally retarded persons and the general public of the true nature of this search — the reasons for caution, as well as the reasons for hope.

Q: Is it realistic to expect to find some cures for mental retardation?

A: There are quite a few areas of research that definitely show promise. Scientists at 1980's Sea Island Conference felt that there is every possibility that cures for mental retardation could be found within the next two decades. There is every reason to be optimistic — but we must not forget that we are still merely on the threshold of the search. The human brain holds more mysteries than any other organ of the body. We are learning how the brain works, and what it can do — but we still have a long way to go.

Q: Can the Association for Retarded Citizens realistically hope to find cures, in light of its limited resources? How can the ARC accomplish something no one else has been able to do?

A: The ARC sees its role in this effort as an advocate for change, an organization dedicated to stimulating and encouraging the search for cures. This is not a new role for the Association. The ARC has traditionally acted as a catalyst to prevent mental retardation, and better the lives of mentally retarded persons. The search for cures is an extension of past efforts in research, legislation, programming and a number of other areas. We should not underestimate the ARC's ability to influence public opinion, and get its message across to public and private funding sources. We have a good record of success in those areas. Perhaps the most important role of the ARC in this effort will be to shift the attitudes of the public and the scientific community from the traditional feeling of "hopelessness" regarding mental retardation.

Q: What does this new goal mean to the local Association? What can the units across the country do to further this effort?

A: The Association's thrust for cures will greatly expand possibilities for action on the local level. For

example, local units can gain additional public attention with a new message of hope: The search for cures is now underway. Mental retardation is no longer regarded as a hopeless, irreversible condition. Additionally, locals can play a key role in supporting legislation and funding directed at cure-related research. They can help publicize new discoveries and ensure their implementation. The importance of gaining public understanding of the Association's new stance toward mental retardation cannot be overemphasized.

A Last Word

"Show me how it works, then prove it" has ever been the motto of the dedicated scientist. Yet, the so-called pragmatic researcher is perhaps the greatest dreamer of our time. He looks at what ought to be and isn't — then charts a path to get there. Sometimes, he breaks a great many rules along the way, simply because the rules don't always work. He knows there's an x and a y. Ergo, there ought to be a z there somewhere.

Knowing where we've been doesn't always show where we're going, but it helps. If the word "cure" seems overly idealistic or unattainable to some, it might be wise to consider just where we were when we started, and where we are now. The fruits of applied research over the last quarter century have led us to a point where we can realistically speak of the prevention of over twenty disorders which can produce mental retardation ... and we can talk of outstanding advances in developmentally oriented treatment, and habilitation efforts that have done much to maximize the lives of all mentally retarded persons...

Now, there is strong evidence that we can go a great deal further. We cannot, at this point in time, say exactly where the search will lead us. Still, the Association for Retarded Citizens had no idea just what it might accomplish when it was formed. We only knew that we had to make the effort ... "cautious optimism" was the byword then, as it is now. But the last word in this phrase has nearly always overshadowed the first. That's why we're where we are today...

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